Caring as We Age: Familial Relationships of Adults with Intellectual Development Disabilities

Thesis

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Abstract

The project goal was to investigate intersections between age, intellectual developmental disability (I/DD), and family caregiving. Specific aims were to explore changes that aging brings to the caring relationship, and investigate families' long term plans and the role the individual with I/DD plays in making life plans. In recent years, individuals with I/DD are living longer and, for the first time in history, many are out-living their primary caregivers. Service delivery systems are not keeping up with this changing demographic and little is known about the caring relationships of individuals aging with I/DD. This is an exploratory study, using qualitative methodology to examine these important relationships. The unique contribution is that the study includes the dual perspectives of both the person with I/DD and a family care provider. This project consisted of two semi-structured, adaptive interviews conducted with pairs of individuals with I/DD, aged 50 and older, and a family care provider. Interviews were recorded and transcribed. Data were analyzed using grounded theory techniques to identify themes in the participants' lived experiences. Results provide a better understanding of how aging affects these family relationships, unmet needs, values associated with family involvement in future planning with an aging person experiencing I/DD, and factors contributing to burden and sense of fulfillment in these family caregiving relationships. Results from this study are expected to inform social work and other human service professions about how best to serve and support these family systems over time.

Dedication

I'd like to dedicate this research to the all individuals and families in the developmental disability community. I truly believe that the most valuable information I learned during this process was not only in formal interviews but also in everyday conversation with individuals I became close to and formed relationships with. It is astonishing the barriers this population faces, and saddening to hear stories of individuals who seem to "fall through the cracks" of service and are not given self-determination in their life decisions. I would specifically like to thank the two families I interviewed for opening their lives and stories to the world.

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Chapter 1: Statement of Research Topic

Introduction

Developmental disability includes a diverse group of chronic conditions with varying levels of severity that affects one or more major life activities (Hammel & Nochajski, 2000). There are various ways to define developmental disability. Primarily the definition includes the following: "Chronic impairments before age 22 that continue indefinitely with limits in at least three of the following: self-care, language, learning, mobility, self-direction, potential for independent living and potential for economic self-sufficiency" (Parish & Lutwick, 2005, p. 346). Examples of developmental disability include: cerebral palsy, Autism Spectrum Disorder, Down Syndrome and intellectual disability, formerly mental retardation (Hammel & Nochajski, 2000). An estimated 1.49% of the population lives with some sort of intellectual or developmental disability. Most research with this population is conducted with individuals under the age of 22 (Braddock, 1999). This is likely due to the fact that intellectual developmental disability (I/DD) diagnoses occur before the age of 22, however this leaves a growing population of adults aging with I/DD unaccounted for and overlooked in research (and possibly, service). Research and information about older adults with I/DD has not kept up with progress made to increase lifespan.

The population of older adults in America is growing rapidly. Within the older adult demographic is a unique, growing population that experiences intersections of I/DD and aging. Fifty years ago, few individuals with intellectual and developmental disabilities (I/DD) were expected to live to see late adulthood, however with improvement in medical technology many can live to old age (Parish & Lucwick, 2005; Glaesser & Perkins, 2013). Very little research

addresses the critical life experiences of people with developmental disabilities after the age of twenty one (McDermott, 1997).

It is reported that current cohorts of individuals with intellectual developmental disabilities primarily live with family care givers (Seltzer et. al, 1989; Williamson & Perkins, 2014; Hammel & Nochaski, 2000). In 2011 it was found that as many as 71% lived with a family member. With the demands that age puts on familial caregivers, there is a need for increased support (Williamson & Perkins, 2014). A great responsibility is placed on families as both children and parents age: future care becomes a huge concern. The need for individual and family support increases and physical, emotional and financial needs become harder to meet as both the individuals with disability and their caregiver age (Parish & Lucwick, 2005).

Statement of the Problem

The changing age structure in America has strong implications for the distribution of caregiving for individuals with I/DD (McDermott, 1997). In recent years many individuals with I/DD have begun to outlive their caregivers. Families need emotional, physical and financial assistance in developing care plans to support their child with I/DD when they are no longer able to provide care (Parish & Lucwick, 2005; Williamson & Perkins, 2014). Research shows that aging parents often want to continue their role as primary caregiver even though alternatives may be available (Perkins, 2013). Many families report benefitting from giving care to a child with I/DD and find fulfillment from being a caregiver (Ali, 2012; Williamson & Perkins, 2014). With acceptance and adaptation, family members are often able to better form long-term care plans (McDermott, 1997). Assistance in long-term care planning includes living arrangements, financial support, employment, recreation and other day-to-day living tasks that the caregiver provided for the individual with I/DD's life (Parish & Lucwick, 2005).

Demand for services for older adults with I/DD is growing faster than the community is able to supply (Parish & Lucwick, 2005). There are limited long-term care resources available for individuals and their families. There is also little support to guide and help families establish a plan that will allow the family member with I/DD to exercise choice and self-determination. Plans are too often last minute or ill-fitting for the family system.

Purpose of the Study

This study aims to explore the unique relationship between individuals aging with intellectual developmental disabilities and their close family members. There seem to be two polarized models of family caregiving depicted in the literature, including that of burden and stress vs. gratitude and fulfillment, both of which seem to be greatly affected by the families' long-term plans. By looking into the lives of caregiving pairs it may be possible to identify positive and negative factors that contribute to the relationship. The study also has an intrinsic goal of reaching out to older adults with intellectual developmental disabilities to explore their views about their relationships. Self-worth, fulfillment and purpose are abstract ideas seldom studied in populations with cognitive disabilities, yet these concepts may provide important and valuable missing information about the population. Furthermore, there is little research conducted with caregiving pairs to form ideas about how the relationship evolves as both persons age.

Future planning is something with which individuals with I/DD and their family members struggle. They have little to no support and at times avoid the topic of future planning completely. This study seeks to let these family systems tell their story and be heard so that families similar to their own may benefit from changes in the future.

Research Objectives

1) To investigate intersections of age, intellectual developmental disability and family caregiving;

2) To explore the changes that aging brings to the caring relationship, on both sides and;

3) To investigate families' long term plans and the role the individual with intellectual disabilities plays in making plans.

Chapter 2: Literature Review

Impacts of age on individuals and relationship

Individuals with I/DD experience aging at a significantly faster rate than adults without I/DD (Parish & Lucwick, 2005). This population is at higher risk for chronic conditions and diseases (Glaesser & Perkins, 2013). Older adults with I/DD are at risk for "potentially earlier and increased occurrence of select normative aging and disability-related processes among adults with developmental disabilities" (Hammel & Nochajski, 2000, p. 6). They are also more prone to dementia, anxiety disorders, phobias, etc. (Gill & Brown, 2000). Many older adults experience a combination of other disorders, diseases or conditions that can result in a loss of motor, sensory, cognitive, intellectual and psychosocial behaviors (Hammel & Nochajski, 2000). Effects of aging also impact community social participation which can be detrimental to an individual's health.

Age plays an important role in the lives of adults with I/DD and their families. Despite the increased aging processes adults with I/DD experience, medical advancement has led to longer lives for these individuals. The average lifespan for individuals with I/DD has increased to be similar to that of a neuro-typical older adult, especially individuals with milder disabilities (Parish & Lucwick, 2005; Glaesser & Perkins, 2013). For example, the average lifespan for individuals with Down Syndrome used to be only 20 years old, now it is around 60-64 (Hammel & Nochajski, 2000). This age increase often means, that for the first time in history, adults with I/DD are outliving their parental caregivers (Parish & Lucwick, 2005).

Siblings often anticipate taking charge of care for individuals with I/DD as parents' age or can no longer provide care. "Siblings and parents are faced with finding a balance in caregiver

expectations related to the sibling with a DD, and they often have to navigate the process of making decisions regarding care for the individual with a DD when parents can no longer perform this function." (Burbidge & Minnes, 2014, p. 149). However, there is very little in depth study of these parent-child or sibling relationships as all family members age. Adults with siblings with I/DD often report close relationships (Burbidge & Minnes, 2014). Adult siblings of a brother or sister with I/DD have shown to be "emotionally and instrumentally involved" from an early age and continue to be through adulthood (Seltzer et. al, 1991). Studies have shown that siblings often step into the role of caregiver not only because they feel responsible but also because they *want* to care for their loved one with I/DD.

Family Members as Caregivers

The push for deinstitutionalization of the I/DD community has come a long way in the past 50 years, however moving towards community living puts more pressure on family caregivers. Parents, often mothers, take over care for their child with I/DD throughout their lifespan (Brown et al, 2006). As parents age and are no longer able to provide care, the responsibility of caregiving is often passed along to siblings and other family members. Family caregivers are in need of support which may involve respite, home/environment adaptation, crisis intervention, assistive devices, personal assistance and often emotional support (Parish & Lucwick, 2005).

Physical health, mental health, and economic hardship are among the stress factors commonly reported by family caregivers for adults with I/DD (Williamson & Perkins, 2014). Mental health concerns for caregivers were reported to be primarily affected by diagnosis and relative level of care need for the individual with I/DD. More severe disability is related to higher level of care needs and more caregiver burden. Not surprisingly, family caregivers who reported greater amount of service needs or unmet needs reported higher caregiver stress.

Additionally, caregivers who are "compound caregivers," which involves caring for than one family member, have an increased level of caregiver burden and stress and report a desire for out-of-home care. (Williamson & Perkins, 2014). Compound caregiving is becoming a very common phenomenon quite similar to the "sandwich generation" of caregivers who are providing care for a parent and a child at the same time.

Although there are many stresses associated with being a caregiver for a loved one with disability there is also positive characteristics associated with providing care. Care often reciprocated from adult with I/DD. They often take responsibilities around the house and provide companionship and support to their caregiver. Caregiver burden was found to be lessened if the individual with I/DD was providing them support (Williamson & Perkins, 2014).

Studies have also shown that the quality of life of families with an individual with I/DD are greatly impacted by the support of the community and having available services (Brown et al, 2006). Affective family support given to adults with I/DD has shown to have profound effects on their quality of life (Seltzer et. al, 1991). Community support provides independence for individuals with I/DD and respite for familial caregivers. The sooner programs and services are made available families may be connected to less caregiver burden. Siblings have a unique relationship. It is usually one of the longest in any two siblings' lives (Seltzer et. al, 1991). This gives adults with I/DD and their changing

Creating a long-term plan

Without proper planning for long-term care when families can no longer provide it, older adults with I/DD unfortunately are often forced into emergency plans that are ill fitted. Without a plan, individuals face being thrust into a lifestyle they are not used to, such as a group home

(Heller, 2000). Lack of planning often results in financial hardship and stress on all parties involved. There is also the issue of waiting lists for long term community care. Reports from 2009 indicate that 221,898 individuals with I/DD are currently on a wait list to receive Home and Community Based Services (HCBS) waiver services" (Kaiser Family Foundation, 2011). These individuals are not being provided formal support and are often relying on "natural" most likely family care.

Families that do plan for future care are hesitant, or unsure, how to include their loved one with disability in the conversation about age, illness, death and the future. Research shows that only about 25-50% of families and individuals with I/DD plan for the future (Heller, 2000). This leads to individuals with I/DD being uninformed about how age affects their future. They are often unprepared for changes in their health, work, leisure and living arrangements (Heller, 2000). Key areas that families must plan for are living, financial, health, guardianship and general lifestyle choices that are likely to change in the future.

It is clear that support systems need to be amended or created to aid individuals and families in creating lives where they can continue to flourish and grow in old age. Currently, long-term services and support for adults with I/DD is primarily funded through a Medicaid program, Home and Community-Based Services (HCBS) waiver program. The waiver was established in 1981 to encourage further deinstitutionalization and community integration for the population with I/DD (Williamson & Perkins, 2014).

Changing Communities and Choice

During the late 1960s, lawsuits about the mistreatment of individuals with I/DD within institutions led to a movement advocating for community-based care. Thousands of individuals

were moved out of institutions and into nursing homes and group homes in the community (Parish & Lucwick, 2005). Although deinstitutionalization was a step in the right direction, for many years society still viewed developmental disability in a medical model (Leiter, 2007). The medical model of disability describes it to be a defect of a person but also something that could not be "cured" or "fixed" (Charlton, 1998). Persons with I/DD were in communities but were still segregated in sheltered work environments and large community living spaces where individuals were not given individualized care or choice.

Over the past twenty years a notable change has occurred in the way society defines and views disability. Charlton (1998) describes it to be a "remarkable and unprecedented paradigm" as views of developmental disability have shifted from the traditional view of sickness and abnormality. There have been gradual improvements in the way communities view members with I/DD. Individuals with I/DD used to be looked at by their communities as burdens that needed to be hidden away. Within the last twenty years, however, society has begun to shift to be more adaptive for all people with differing abilities. There are a multitude of groups and proposed legislature advocating for individuals with I/DDs rights and fighting for continued desegregation (Parish & Lucwick, 2005). Medical and other professional schools around the country have little to no curriculum involving the unique care needs of adults and older adult with I/DD. The growing population has created a need for education and some schools have added lessons on provide person-centered care for this population.

Older adults with I/DD are experiencing numerous changes in their lives. They experience normal aging related conditions at higher frequencies and rates than the normal population. They are also often experiencing social and familial change. Family members are also aging, often primary caregivers (parents) pass away and siblings step into the caregiving

role. Other times adults with I/DD are placed out of their homes into community living homes or group homes. Without proper planning individuals and families experience greater stress and burden. Families who have open communication and dialogue when making decisions about the future are likely to have more success with transitions in the future. Open communication also will promote self-determination and give the family member with I/DD. Adults with developmental disabilities are too often spoken for in situations and the same is for research conducted with this population. In an attempt to include and encourage exploration of research with adults with I/DD it was vital that their voice was heard.

Chapter 3: Methodology

Research Design

A qualitative design was chosen for this study to seek a greater understanding of participants' experiences and stories. Qualitative research explores phenomena through an inductive process of understanding, based on distinct methodological traditions of inquiry that investigate a social or human problem (Creswell, 1998). Qualitative coding processes take a unique approach to essentially turn words and stories into themes, noting similarities and differences between participants. Qualitative research allows the researcher to build a holistic image of an individual's experiences and the experiences of a group or population (Padgett, 2004).

The study aims to explore the unique and changing relationships that older adults with I/DD have with their family members. The qualitative research process involving in-person interviews followed by inductive thematic coding best suits the research aims of the study. All materials and protocol for the study were submitted and approved by Ohio State's Institutional Review Board.

Sampling Procedure

Participants included a convenience sample of older adults with I/DD and one of their close family members. Usually individuals 65 and older are considered to be "older adults" in America. It was found appropriate to include individuals with I/DD who are 50 years and older (Parish & Lucwick, 2005) by virtue of the way that these individuals are known to age prematurely. The study goal of 10-12 caregiving "units," including individual with I/DD and one of their close family members, was selected to achieve a sample size sufficient to develop a

broad picture of the experiences and achieve saturation (no new experiences emerging thematically). However, only two units were completed by the study period ending. Reasons for failures in recruitment are explored below. Other than age, exclusion criteria were disability diagnoses without an intellectual disability component i.e., individuals with developmental disabilities that are strictly physical, such as cerebral palsy, and inability to respond to questions in an interview setting.

Recruitment was conducted through the Ohio SIBS program at Ohio State University's Nisonger Center, Goodwill Columbus, and Creative Foundations. Flyers also were placed on bulletin boards in senior centers around the Columbus Area. The flyers advertised the requirements to take part in the study including:

- A caregiver who is a family member of an older adult with I/DD
- An older adult with intellectual developmental disability (aged 50 and older)
- A one-time, in-person one hour interview
- $15 Target gift card for each participating family member

Data Collection Procedures

Data were collected through in-person one hour interviews involving both the individual with I/DD and a family caregiver. The inclusion of the pairs encouraged collaboration and encouragement between the two siblings for the interview content, as well as providing information from their different perspectives. For example, they helped each other remember different events and explored differences and similarities in their experiences. Amazing dynamics emerged between the family members in the interviews.

Interviews were recorded and later transcribed, then thematically coded. Participants were each offered a $15 Target gift card as an incentive for participating in the study.

Demographics

The sample included two pairs of an older adult with I/DD and their family caregiver. There was one white male with I/DD diagnosis, aged 60, with a female white caregiver (younger sister) aged 55. There was one white female participant with I/DD, aged 61, with her white female caregiver (older sister), aged 66. In both cases the caregiver was their sister. Both individuals had diagnosis of intellectual disability and attended Goodwill Sage Senior program for adults with I/DD older than 45. Both individuals and their caregivers were residents of Central Ohio.

Procedures

The data in this study were collected through in-person interviews after participants were screened-in with a set of preliminary questions. The data collection interview was adapted around specific questions about the changes that aging has brought to the individual with I/DD, his or her caregiver, and their relationship. The interview was semi-structured. If only one of the family members had answered a question, the researcher would ask the other to share their experiences in order to assure that their voice also was being heard. If a question's response was not elaborated on, the researcher probed with related questions to help make it easier to understand and answer for the participants. An interview partner was also present during the interviews to take notes about the interview to augment and help interpret the recording. The partner took note of body language and interaction between the participants, as well as other

themes that may not be verbally recorded. These notes also served as security in case something went wrong with the recorders during the interview.

Each interview audio recording was later transcribed verbatim. The transcripts were then thematically coded. Participants were given a non-identifying number and were not identified anywhere else in the research process. Informed consent was given before beginning the interview. The one-time interviews were approximately one hour in duration.

Data Analysis

Qualitative coding was used to identify general themes, including repetitions and differences to that appeared. Cutting and sorting of interviews was then used to further identify subthemes and to better develop a sense of what is similar and different between the two sibling units.

Thematic coding produced 10 themes.

- Effects of age on caregivers
- "compound caregiving"
- Intersections of age and I/DD
- Future planning: Living arrangements and independence
- Worries about the future
- Optimism
- Extended family involvement
- Loss of family members
- Sibling taking on parenting role
- Effects of programs
- Past: Not enough support

The following table was used to sort quotes after themes were identified:

Italics: Adult male with I/DD and younger sister caregiver

Non-Italics: Adult female with I/DD and older sister caregiver

THEME	QUOTE
Loss of family members	"I brought my father and L up from Louisiana, and he passed away within five months" -B
	"my mother died in 98' and my father died in 2004" -B
	"We've had a lot of family that has helped. Now unfortunately, all of those aunts and uncles are dying off so… it falls more on me" -B
	"I used to spend time with my grandma G. every couple of nights a week maybe…I kind of miss that after she passed away she was 66, she passed away she had angina. But I guess I was her favorite grandson." –M
Making living arrangement plans	"We had always planned for L to live with us" -B
	"…we built it knowing that L would eventually come live with us" -B
	"I don't know it just was always in my mind that M would come with me one day. Mom asked him if he wanted to live with me or my sister he picked me!" -S
Sibling taking on parenting role	"we're sisters but I have become her mother too…" -B
	"I'm the chief interpreter of what she says or tries to say, because she can't get the words out right." -B
	"We've got a lot of disabled issues here…a lot of the responsibility mainly falls on me" -B
Extended family involvement	"We have a lot of family get-togethers and things which makes it nice."
	"[my daughter] is the second person who would be in charge if something happens to me. She would have a lot on her plate…" -B
	"We have a lot of family get-togethers because we have a huge family" -B
Intersections of Age and DD: Dementia	"she's in the beginning to middle stages of dementia" -B
	"…the words that just aren't there anymore, or they come out totally unrelated or unintelligible" –B "Oh, yeah" -L
	"She used to on long bike rides and walks and now we're careful about that and she's not to do it unless I'm home" -B
	"I'm more careful now" –L
	"L had a lot of health issues when she came but I... got her connected with all sorts of doctors and she's doing... really a lot better when she did when she lived down in Louisiana" -B
Worries about the future	"Lknows what happens when people get into advanced stages of dementia and she knows she might not always be able to live at home…it's a big worry" –B
	"L is very concerned about what will happen to her…especially if something happens to me."-B

	"Now that's an eye-opening experience when we first got her into the program and to see the amount of individuals that just fall through cracks its…" –B "It's pretty sad…it's really sad" -L
	"I think I would like that better than a group home because some people aren't fit to group homes…some people but I don't think M: not for all, I don't think it'd be for me." -M
Optimism	"you just have to forge ahead, there's nothing else you can do" -B
	"Well it's different right now for me, but I do it" –L
	"Yeah, we're just taking it day by day... We're just hoping for the best." -M
	"If we have any problems we'll just talk about em'. if I don't like something... I'll let her know"-M
	"I wish we'd have had these opportunities y'know when m was a little younger but we just say were gonna enjoy ourselves while we can" -S
	"My advice would be to an advocate. I know nobody expects to be in that situation but you need to learn pretty darn quick and be an advocate and reach out and ask for help and Accept help. Always stay involved. and plan, plan, plan ahead" -S
Effects of Programs	"it's good for L to be able to get out every day and have her circle of friends and activities that's not totally dependent on me" -B
	"I encourage her too cause I know how she feel I mean I been through it and I've been trying to y'know encourage her. And I'm pretty close to her so I do bowling with her. We do bowling for Special Olympics and stuff." -L
	"but were so blessed to find Sage and M has come here. He's made friends he participates in activities, especially Boo's wellness" -S
Effects of Age on Caregivers	"My husband always helped, but now he is disabled…totally blind" -B
	"I don't think the family can do it all" -B
Independence	*"so more or less things around M have changed. M is still very independent" -S*
	"we think it's important that m has his own space but uh y'know now he has a bedroom and a social area in the basement but we would like him to be on the floor with us so that we can y'know talk more and just uh have m engaged with us when he wants to we'd like you to y'know be around to talk to us" -S
Past: Not enough support	*"y'know my parents didn't know anything about individuals with disability acts or anything of that nature it was just "everybody paddles their own canoe" and so I guess finally something happened between the county and the state" -S*

Chapter 4: Results

Effects of age on caregivers.

Only one of the caregivers really talked about herself and age. She spoke about the stress that age has brought to her family life as she ages along with her husband and younger sister. She mentioned the disabilities "piling up" causing worry about the future. She expressed her concerns about what would happen to her loved ones if something were to happen to her. She still works full-time and is extremely concerned about the future care if something were to happen. Tentative plans are in place but it would be very problematic.

Compound caregiving.

Compound caregiving is the experience of being a caregiver for multiple family members at once. Both caregivers that were interviewed experienced being the primary caregiver for two family members at once. Both cared for their siblings, one a younger sister and one an older brother. In addition, one cared for her mother who was in hospice at the time and the other cared for her husband who was experiencing loss of vision and hearing. The stress created on one person being responsible for so much really seemed to weigh heavily on the caregivers. While not stated explicitly, it was clear through their stories that these caregivers were in need of more support.

Intersections of age and I/DD.

This theme arose from asking the pairs about the changes that age as brought to their life in relation to their disability. One participant spoke of how he is actually getting healthier with an exercise regime and activities at his day program. He had very little to say about negative changes in his health related to age. On the other hand, the other participant is experiencing

early- to middle-stage dementia, a diagnosis that is often seen to be sped up in adults with I/DD. She has begun to find it harder to say what she means. While the thoughts are there it sometimes doesn't translate into words. Her sister served as her main "translator" in moments of confusion or miscommunication. The two have open communication about dementia and have been seeing doctors. They are working together to adapt to these the new changes brought by dementia.

Future planning: Living arrangements and independence.

Both pairs of participants had at least done some future planning for living arrangements for their sibling with I/DD. In both cases independence was very important to the family members when deciding where they were going to live. Both families also knew years ago that they would have their sibling live with them when their parents could no longer. One caregiver and her husband included an apartment which they call the "sister-in-law suite" on the top floor of their house when they built it knowing her younger sister would live with them. The other caregiver and her brother are going through a living transition period. Their mother is no longer able to care for him so they are in the process of building on to their house to allow him to have privacy and independence that he enjoys in his parents' basement.

Worries about the future.

The caregivers both have contemplated what would happen if something happened in the future that made them unable to care for their sibling with I/DD. There are tentative plans in place for who would then become the primary caregiver. More concerned about the future are the siblings with I/DD. They are very worried about something happening to their sisters leading to an out of home, community placement. They have heard stories of friends in group homes that have not had good experiences and are very upset at the idea of something happening to their loved one.

They are aware of the vulnerable positions that their friends have been in and fear that these same situations may happen to them. Their sisters however assure both of them that they will not be placed in a group home even if something does happen to them in the future.

Optimism.

Although there was a large amount of worry and concern about the future expressed by individuals and caregivers, there was a tone of optimism in what they spoke of. They talked about being open with each other, forging ahead and taking things one day at a time. It is clear that these families were not going to let circumstances get them down.

Extended family involvement.

Both groups of siblings have a large extended family in Central Ohio that offer support and respite for care of their sibling. Especially in the past when public services were not available, extended family played a large role in providing care.

Loss of family members.

Age has certainly had an effect on family members outside the sibling pairs. Their extended family has slowly begun to pass away as they have gotten older. The families and individuals with I/DD have been profoundly affected by the death or their loved ones, most notably their mothers. In both situations their mothers were their primary caregivers well into adulthood. One participant's mother died when they lived in Louisiana causing her and her father, who passed away several years later, to move to Central Ohio to live with her older sister. The other participant has lived with his parents his whole life. His mother is in hospice which is forcing him to deal with the hard to grasp topic of death and dealing with grief and loss following it. His sister talks to him about these subjects but has worries what he is actually experiencing.

Sibling taking on parenting role.

This is one of the themes that the pairs of siblings did not both agree on. The sisters talked about after their mother died the older sister and caregiver took on a more parental or motherly role in providing care for her younger sister. This did not manifest in the other sibling relationship: they really seem to view and treat each other as peers.

Effects of programs.

Both groups of sibling spoke of the immense benefits of finding a good fit of a day program for the individual with I/DD to attend. Finding a good program provided support to both siblings. For the sibling attending the program it provided them with activities, work opportunities and most importantly friendship and community. For the caregiver sibling it provided them with respite and also a community of support to help connect them with resources. Both siblings wished that they would have found their programs earlier.

Past: Not enough support.

The importance of finding a good program was also joined with the lack of support and programming in the past. Both groups of siblings experienced issues finding services for persons with disabilities. There was a lack of availability of programs to begin with and what did exist was not of good quality. They relied heavily on family members to help with care and respite.

Chapter 5: Discussion

Summary of the Results

The ability of families to plan was affected by both optimism and worries about the future. Individuals with disabilities worried about losing loved ones and being placed out of familial care and into community homes. Family caregivers were more concerned about other aging family members and the burden of caring for multiple people at once. In both cases family members assured their loved ones that they would not be placed in a community living setting. Although families were dealing with a lot and having to prepare for and cope with change, they remained optimistic about what is to come. The voice and stories of the individuals with I/DD have a great impact on the results of this study. In both situations they had open communicating relationships with their sisters about their desires in the present and in the future.

Limitations

The first true limitation faced in this study was issues with recruitment. It was more difficult than anticipated to recruit adults with I/DD and caregivers willing to be a part of the study. Often times, initial contact with participants in a day program where I am an intern seemed promising. Numerous individuals fit the study eligibility criteria. However, when flyers were taken home to be relayed to family members' communication was hard to establish.

An important and hard decision I had to make when developing the criteria for my project was how to determine what "level of disability." My mission, in interviewing individuals with I/DD was to give them a voice and allow them to tell their story. But, I was unsure about how to allow non-verbal, deaf, or individuals using Augmentative and Alternative Communication (AAC) devices to tell their story. This is one of the greatest flaws in a lot of

research involving populations with I/DD. It is my hope that this trend changes in the future. I would be very interested in doing a study to learn the stories of individuals who might not tell them the same way as most people.

Originally, when thinking of research questions about this population I felt I must exclude individuals who did not have a caregiver whom at the time I assumed would be their guardian. As I got to know more and more individuals I realized many of them did not have family members in town or at all. I was even more interested to learn that many of them were their own guardians. A misconception I had in the beginning of the process led me to leave out an important group of individuals from my study. Of course the relationships of individuals and paid caregivers is a completely different area of study entirely but still should not be discounted.

Practice Implications

Social workers and other professionals could use these themes to better serve individuals with I/DD and their family members as they age. For example the theme of "Effects of programs" emerged. This theme illustrated the importance of finding a good fit in a program for the family member with I/DD. Families also mentioned the lack of support in past years for their loved one with a disability, and the sooner that services can be utilized the better. Services utilized earlier in life help individuals with I/DD and their family members establish themselves in communities that understand their family system and provide support. This information will also help inform policy makers when considering aid and support for these families.

Future Research Recommendations

While the information this study found is very important for advocating for these families there is a need for more research to fully support the findings. If the objectives of this study

were to be explored in the future there would need to be different methods of recruitment utilized. Reaching out to caregiver groups and finding a way to make it more convenient and appealing would be suggested. It also would be interesting to explore how individuals without family support make decisions about the future with their legal guardians. Finally, exploring the topic of future planning with younger adults with I/DD and their families would be very beneficial. This information would help understand the experiences of families currently at the beginning stages of planning for the future and could encourage families to have these conversations with their loved ones.

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Appendix A

Approval from IRB

Behavioral and Social Sciences Institutional Review Board

Office of Responsible Research Practices
300 Research Administration Building
1960 Kenny Road
Columbus, OH 43210-1063

Phone (614) 688-8457
Fax (614) 688-0366
www.orrp.osu.edu

December 8, 2014

Protocol Number:	**2014B0347**
Protocol Title:	**CARING AS WE AGE, Audrey Begun, Emily Kowal, Social Work**
	Request to amend the research dated October 31, 2014 (add Creative Foundations as a research site; revise protocol to reflect that flyers will be placed on bulletin boards in senior centers and to include additional research site).
Type of Review:	Amendment #01—Expedited
Approval Date:	**December 4, 2014**
IRB Staff Contact:	Amanda Thompson Phone: 614-688-1059 Email: Thompson.2024@osu.edu

Dear Dr. Begun,

The Behavioral and Social Sciences IRB **APPROVED** the above referenced research.

Note that if applicable, informed consent (and HIPAA research authorization) must be obtained from subjects or their legally authorized representatives and documented prior to research involvement. The IRB-approved consent form and process must be used. Changes in the research (e.g., recruitment procedures, advertisements, enrollment numbers, etc.) or informed consent process must be approved by the IRB before they are implemented (except where necessary to eliminate apparent immediate hazards to subjects).

It is the responsibility of all investigators and research staff to promptly report to the IRB any serious, unexpected and related adverse events and potential unanticipated problems involving risks to subjects or others.

This approval is issued under The Ohio State University's OHRP Federalwide Assurance #00006378. All forms and procedures can be found on the ORRP website – www.orrp.osu.edu. Please feel free to contact the IRB staff contact listed above with any questions or concerns.

Michael Edwards, PhD, Chair
Behavioral and Social Sciences Institutional Review Board

Full Accreditation

hs-017-03 Approval Amend
Version 05/18/10

Appendix B

Letters of Support

goodwill Columbus

August 28, 2014

Dr. Audrey Begun, Principal Investigator
The Ohio State University
College of Social Work
325 Stillman Hall
Columbus, OH 43210

Dear Dr. Begun,

This is a letter of support for the research project Caring as We Age. As the Chief Mission Officer in a non-profit that delivers services to individuals aging with intellectual developmental disabilities and their primary caregivers, I was happy to agree to the request made by Ms. Emma Kowal for assisting in the study. My understanding is that the study is designed to explore the relationship between older adults with developmental disabilities and their primary caregivers. I believe that investigating intersections of age, intellectual and developmental disability and caregiving will be helpful to the population my agency provides for.

The extent of participation, as I understand it, includes the following:

1. Providing a formal letter of support from my agency to be submitted to Ohio State University's Institutional Review Board (IRB)
2. To aid researches in distribution and posting fliers advertising the study
3. Providing space for researchers to interview participants in my agency

Thank you for potentially including our clients in your project.

Sincerely,

Mary Vail, MRC
Chief Mission Officer

Building **INDEPENDENCE**, **QUALITY of LIFE** and **WORK opportunities** for individuals with disabilities and other barriers.
1331 Edgehill Road, Columbus, Ohio 43212 P 614-294-5181 F 614-294-6895 *www.goodwillcolumbus.org*

57 N. Sandusky Street
Delaware, Ohio 43015

Toll-Free: (877) 345-6733
FAX: (855) 832-2121
www.CreativeFoundations.org

Dr. Audrey Begun, Principal Investigator
The Ohio State University
College of Social Work
325 Stillman Hall
Columbus, OH 43210

October 15, 2014

Dear Dr. Begun,

This is a letter of support for the research project *Caring as We Age*. As an Executive Director in a program that delivers services to individuals aging with intellectual developmental disabilities and their primary caregivers, I was happy to agree to the request made by Ms. Emma Kowal for assisting the study. My understanding is that the study is designed to explore the relationships between older adults with developmental disabilities and their primary caregivers. I believe that investigating intersections of age, intellectual, and developmental disability and caregiving will be helpful to the population my agency provides for.

The extent of participation, as I understand it, includes the following:

1. Providing a formal letter of support from my agency to be submitted to Ohio State University's Institutional Review Board (IRB)
2. To aid researchers in distribution and posting fliers advertising the study
3. Include an announcement in agency newsletter
4. Providing space for researchers to interview

Thank you for potentially including our clients with your project.

Sincerely,

David J. Robins

David J. Robins
Executive Director

Appendix C

Recruitment Materials

THE OHIO STATE UNIVERSITY
COLLEGE OF SOCIAL WORK

CARING AS WE AGE

A RESEARCH STUDY

An Ohio State University research project exploring the relationships between older adults with intellectual developmental disabilities and their familial caregivers.

participation in this study consists of:

a 45-60 minute interview with you and your family member with intellectual developmental disability.

eligibility to participate:

about 10 pairs of an individual with intellectual developmental disability who is 50 years or older and a close family member.

Each participant in each pair will receive a $15 Target gift card

To find out more information about this study, please contact Emma Kowal at kowal.25@osu.edu or call (937)272-8898

This study was approved by the Ohio State University Institutional Review Board on (date)

Appendix D

Informed Consent form family member and participants who are their own guardian

The Ohio State University Consent to Participate in Research

Study Title:	Caring as We Age
Researcher:	Dr. Audrey Begun, a professor in social work at The Ohio State University is the primary investigator for this study. Emma Kowal is a senior honors social work student at The Ohio State University who will be engaging in data collection and analysis for the entirety of the project.

This is a consent form for research participation. It contains important information about this study and what to expect if you decide to participate. Please consider the information carefully. Feel free to ask questions before making your decision whether or not to participate. If you decide to participate, you will be asked to sign this form and will receive a copy of the form to keep for your records.

Your participation is voluntary. You may leave the study at any time. If you decide to stop participating in the study, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled. Your decision will not affect your future relationship with The Ohio State University.

Purpose: The purpose of this study is to explore the changes that aging brings to the relationship between adults with intellectual developmental disabilities and their close family members.

Procedures/Tasks:

If you take part in this study, you will be asked to:

- Complete one interview conducted by Emma Kowal. The interview is estimated to last about 60 minutes.
- The interview, (with your permission) will be audio recorded.

Risks and Benefits:

There are no immediate, obvious benefits to you for taking part in this research study, other than the opportunity for you to tell your story. There potentially are benefits to society and families like yours based on the study results.

This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day. There are no known additional risks to those who take part in this study.

Confidentiality:

Efforts will be made to keep your study-related information confidential. However, there may be circumstances where this information must be released. For example, personal information regarding your participation in this study may be disclosed if required by state law. If information leading to a suspicion of elder abuse is disclosed, it will need to be reported to the proper authorities. Also, your records may be reviewed by the following groups (as applicable to the research):

- Office for Human Research Protections or other federal, state, or international regulatory agencies;
- The Ohio State University Institutional Review Board or Office of Responsible Research Practices;

Incentives:

Each participating individual will be offered at $15 Target gift card.

Participant Rights:

You may refuse to participate in this study without penalty or loss of benefits to which you are otherwise entitled. If you are a student or employee at Ohio State, your decision will not affect your grades or employment status.

If you choose to participate in the study, you may discontinue participation at any time for any reason without penalty or loss of benefits. By signing this form, you do not give up any personal legal rights you may have as a participant in this study.

An Institutional Review Board responsible for human subjects research at The Ohio State University reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

Contacts and Questions:

For questions, concerns, or complaints about the study, or you feel you have been harmed as a result of study participation, you may contact Dr. Audrey Begun at begun.5@osu.edu or by calling her at 614.292.1064.

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.

[continue to last page]

Signing the consent form:

I have read this form and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form.

Printed name of subject	Signature of subject
	AM/PM
	Date and time

Investigator/Research Staff

I have explained the research to the participant or his/her representative before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

Printed name of person obtaining consent	Signature of person obtaining consent
	AM/PM
	Date and time

Appendix E

Informed Consent for Individual with I/DD if authorized consent needed

The Ohio State University Consent for a Family Member to Participate in Research

Study Title:	Caring as We Age
Researcher:	Dr. Audrey Begun, a professor in social work at The Ohio State University is the primary investigator for this study. Emma Kowal is a senior honors social work student at The Ohio State University who will be engaging in data collection and analysis for the entirety of the project.

This is a consent form for research participation. It contains important information about this study and what your family member should expect if you two decide he or she will participate. Please consider the information carefully. Feel free to ask questions before making your decision about whether or not to participate. If you two decide that your family member will participate, you will be asked to sign this form on his or her behalf, and will receive a copy of the form to keep for your records.

Pparticipation is voluntary. Your family member may leave the study at any time. If he or she decides to stop participating in the study, there will be no penalty or loss of any benefits to which he or she is otherwise entitled. Your decision will not affect future relationships with The Ohio State University.

Purpose: The purpose of this study is to explore the changes that aging brings to the relationship between adults with intellectual developmental disabilities and their close family members.

Procedures/Tasks:

If your family member takes part in this study, he or she will be asked to:

- Complete one interview conducted by Emma Kowal. The interview is estimated to last about 60 minutes.
- The interview, (with your permission) will be audio recorded.

Risks and Benefits:

There are no immediate, obvious benefits to your family member for taking part in this research study, other than the opportunity for him or her to tell his or her story. There potentially are benefits to society and families like yours based on the study results.

This research is considered to be minimal risk. That means that the risks associated with this study are the same as what your family member faces every day. There are no known additional risks to those who take part in this study.

Confidentiality:

Efforts will be made to keep your family member's study-related information confidential. However, there may be circumstances where this information must be released. For example, personal information regarding participation in this study may be disclosed if required by state law. If information leading to a suspicion of elder abuse is disclosed, it will need to be reported to the proper authorities. Also, records may be reviewed by the following groups (as applicable to the research):

- Office for Human Research Protections or other federal, state, or international regulatory agencies;
- The Ohio State University Institutional Review Board or Office of Responsible Research Practices;

Incentives:

Each participating individual will be offered at $15 Target gift card.

Participant Rights:

Your family member may refuse to participate in this study without penalty or loss of benefits to which he or she is otherwise entitled. If you or your family member are a student or employee at Ohio State, your decision will not affect grades or employment status.

If your family member chooses to participate in the study, he or she may discontinue participation at any time for any reason without penalty or loss of benefits. By signing this form, you do not give up any of his or her (or your own) personal legal rights your family member may have as a participant in this study.

An Institutional Review Board responsible for human subjects research at The Ohio State University reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

Contacts and Questions:

For questions, concerns, or complaints about the study, or you feel you have been harmed as a result of study participation, you may contact Dr. Audrey Begun at begun.5@osu.edu or by calling her at 614.292.1064.

For questions about your family member's rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.

[continue to last page]

Signing the consent form:

I have read this form and I am aware that I am being asked to authorize my family member'js participation in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to have my family member participate in this study.

I am not giving up any legal rights for myself or my family member by signing this form. I will be given a copy of this form.

I am legally authorized to consent for my family member.

Printed name of subject (your family member with I/DD)	

Printed name of person authorized to consent for subject (when applicable)	Signature of person authorized to consent for subject (when applicable)
Relationship to the subject	Date and time AM/PM

Investigator/Research Staff

I have explained the research to the participant or his/her representative before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

Printed name of person obtaining consent	Signature of person obtaining consent AM/PM Date and time

Appendix F

Screening Script

1. What is the nature of your family connection? (son/daughter/spouse/sibling/etc…)

2. Can you briefly describe the nature of your _____'s intellectual disability?

3. How old is _____?

4. Can you briefly describe your role in _____'s care?

5. What might other families learn from your family? (if not illegible)

• Arrange interview place, date and time

• Clarify that they will need to provide transportation and that both will be there

• Clarify consent followed by interview

• Clarify incentive

• "Thank you and we'll see you on [day and date] at [time] at [place]"

• Also mention how they will recognize you if meeting in public place

Appendix G

Interview Questions

1. How old are you?

2. Do you two live together?

-If yes, since when/for how long?

-If no, with whom do you live?

3. Can you tell me some things about your relationship?

-How did you become _____ 's primary caregiver? [to care provider]

4. How have your needs changed with age?

-Over the last few years what has changed?

5. How has your life changed as you've gotten older?

6. How has your relationship changed as both of you have aged?

7. How have you worked out your caring relationship?

8. What plans, if any, are in place for care in the future?

-What can you tell me about HOW you went about developing these plans, or will develop these plans?

9. What are the changes the two of you have experienced in the world around you and in the service delivery system?

10. What about the service support system availability has made the relationship easier?

11. What challenges have you faced?

12. What has been helpful?

13. What advice would you give to families similar to yours?